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Abstract The purpose of this study was to evaluate how activity pacing relates to physical activity and health-related quality of life a year post-rehabilitation in adults with multiple sclerosis. 68 adults with multiple sclerosis (mean age= 42 ± 11 years) filled in questionnaires on their active engagement in pacing decisions and perceived difficulty in preventing overactivity (5-point Activity Pacing and 2-point Risk of Overactivity Questionnaire), fatigue (7-point Fatigue Severity Scale), physical activity (adapted Short Questionnaire to Assess Health-Enhancing Physical Activity) and health-related quality of life (RAND-12 Health Survey) post rehabilitation and at one year follow up, as part of the Rehabilitation, Sports and Active lifestyle study (a nationwide multi-centre program aimed at stimulating and promoting an active lifestyle in rehabilitation in the Netherlands). Multilevel modelling was used to analyse the associations between activity pacing, fatigue, physical activity and health-related quality of life a year after discharge from rehabilitation. No associations were found between activity pacing and physical activity ($\beta = -0.21$; $p > 0.05$), and between activity pacing and health-related quality of life ($\beta = -0.10$; $p > 0.05$) at long-term. Fatigue was negatively related to health-related quality of life ($\beta = -0.35$; $p < 0.001$). Perceived risk of overactivity moderated the association between fatigue and health. These findings suggest that persons who experience decreases in health-related quality of life with increased fatigue, are more likely to be engaging in 'overactive' behaviour. The lack of associations between activity pacing and physical activity, and between activity pacing and health-related quality of life suggests there is no clear strategy among persons with MS that is successful in improving physical activity and quality of life either in short or long-term when no interventions are introduced.

Keywords Engagement in pacing and perceived risk of overactivity, physical activity, fatigue, health—related quality of life

Introduction

For people with multiple sclerosis (MS), the experience of fatigue symptoms can greatly impair their quality of life (Merkelbach et al., 2011; Amato et al., 2001). While a link between fatigue and measures of physical disability has been established in MS (Molt et al., 2006), less is known about how strategies to cope with fatigue such as activity pacing, influence physical activity on a day-to-day basis. The aim of the present is to examine how activity pacing relates to the

development of physical activity and health-related quality (HRQoL) of life in adults with MS a year after discharge from rehabilitation.

Methods

Participants

This study is part of a multicentre longitudinal study (Rehabilitation, Sports and Active lifestyle; ReSpAct) to evaluate the nationwide implementation of an active lifestyle program (Rehabilitation, Sports and Exercise) among persons with a wide range of chronic diseases and/or physical disabilities in Dutch rehabilitation (Alingh et al., 2015). Data from 14, 33 and 52 weeks after discharge from rehabilitation of persons with MS, selected from the ReSpAct dataset were used for the current study.

Outcome measures

Engagement in pacing and perceived risk of overactivity was assessed with the Activity Pacing and Risk of Overactivity Questionnaire (Alingh et al., 2015). Physical activity was assessed with an adapted version of the Short Questionnaire to Assess Health-Enhancing Physical Activity (Wendel-Vos et al., 2003). Fatigue was measured using the Fatigue Severity Scale (Krupp et al., 1989). HRQoL was assessed using the RAND 12-Item Health Survey (Selim et al., 2009). In addition, personal (age, gender, body mass index) characteristics were also collected.

Statistics

Multilevel analysis was performed to determine how activity pacing were related to the development of physical activity behaviour and health-related quality of life a year after rehabilitation, by using MLwiN (Charlton et al., 2017). The multilevel analysis created models of physical activity and HRQoL. A p-value lower than 0.05 was regarded as statistically significant.

Results

A total of 68 adults with MS (mean age= 42 ± 11 years) were included in this study. Engagement in pacing were 5.2 ± 1.0, 5.1 ± 1.2 and 5.1 ± 1.0; physical activity were 978.9 ± 930.1, 846.3 ± 822.7 and 711.1 ± 702.6; and HRQoL were 36.0 ± 8.6, 37.6 ± 8.3 and 38.5 ± 7.3 at 14, 33 and 52 weeks respectively.

No associations were found between activity pacing and physical activity ($\beta = -0.13$; $p > 0.05$), and between activity pacing and HRQoL ($\beta = -0.15$; $p > 0.05$) over time (table 1). Body mass index was related to lower HRQoL ($\beta = -0.33$; $p < 0.001$). Age was positively related to HRQoL ($\beta = 0.28$; $p = 0.004$). Fatigue was negatively related to HRQoL ($\beta = -0.33$; $p < 0.001$). Perceived risk of overactivity moderated the association between fatigue and HRQoL ($\beta = -0.13$; $p = 0.036$).

Table 1. Multilevel models of physical activity and HRQoL a year after rehabilitation. * = significant difference at p<0.05.

Variable Outcome	Gender	Age	Body mass index	Fatigue	Engagement in pacing	Perceived risk of overactivity	Engagement in pacing X Fatigue	Perceived risk of overactivity X Fatigue
	β (S.E.)	β (S.E.)	β (S.E.)	β (S.E.)	β (S.E.)	β (S.E.)	β (S.E.)	β (S.E.)
Physical activity	-0.33 (0.23)	-0.01 (0.11)	-0.03 (0.11)	-0.04 (0.10)	-0.13 (0.10)	0.13 (0.09)	0.03 (0.09)	-0.12 (0.08)
HRQoL	0.36 (0.19)	0.28 (0.10)*	-0.33 (0.09)*	-0.35* (0.08)*	-0.15 (0.09)	0.04 (0.08)	0.02 (0.07)	-0.13 (0.06)*

Conclusion

There is a paucity of research that has examined how activity pacing relates to the development of physical activity and health-related quality of life in MS, and the exploration of long-term data in this study provides important insights. We found no associations between naturalistic pacing behaviours and physical activity, and between pacing behaviours and health-related quality of life one year after discharge from rehabilitation. However, fatigue was related to low health-related quality of life. Also, perceived risk of overactivity moderated the association between fatigue and health-related quality of life. Altogether, the study findings suggest there is no clear strategy among persons with MS that is successful in improving physical activity and quality of life either in short or long-term when no interventions are introduced. Equally, people with MS demonstrating a high perceived risk of overactivity and a decreased health-related quality of life in the context of increased fatigue may benefit from an intervention to manage fatigue and approach activity in an effective way. There is the need to develop goal-directed interventions.

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